



**Issue Number
414**

August 26, 2005

Published 12 times a year by
John S. James
AIDS Treatment News
1233 Locust St., 5th floor
Philadelphia, PA 19107
800-525-1710

Contents

Hurricane Katrina HIV-Related Information..... 2

We compiled some Web links and telephone numbers for HIV-relevant information, especially on medical care. Check online at www.aidsnews.org/katrina for the latest version.

Communication in a Disaster: Success of Text Messages..... 4

Text messages on cell phones got through when other communication was out -- as it has in other disasters. Governments, companies, and individuals should build on this success for future emergencies.

Katrina: Disaster Notes..... 5

Notes on race, on how to respond when government does not, on ineffectual fundraising, and on misleading "official" figures.

Campaign to End AIDS Postpones Most Caravans, Some Events. 6

The Campaign to End AIDS (C2EA) postponed many but not all of its scheduled events, at the request of local organizers affected by Hurricane Katrina.

U.S. Conference on AIDS Will Go Forward in Houston; New Scholarships, September 16 Deadlines..... 7

The National Minority AIDS Council extended the registration deadline and announced new scholarships in response to the disaster, and decided to go forward with its U.S. Conference on AIDS in Houston, September 27 to October 2.

Medicare HIV Fact Sheet: Caution re January 2006..... 7

About 20 percent of people in HIV care are on Medicare, and will need to decide on a Medicare drug plan by January 2006. It will be especially important for those who are also on

AIDS Treatment News

Subscription and Editorial Office:

AIDS Treatment News
Philadelphia FIGHT
1233 Locust St., 5th floor
Philadelphia, PA 19107
800-TREAT-1-2 toll-free U.S. and
Canada

fax: 215-985-4952

email: aidsnews@aidsnews.org

web: <http://www.aidsnews.org>

Editor and Publisher: John S. James

Statement of Purpose:

AIDS Treatment News reports on experimental and standard treatments, especially those available now. We interview physicians, scientists, other health professionals, and persons with AIDS or HIV; we also collect information from meetings and conferences, medical journals, and computer databases. Long-term survivors have usually tried many different treatments, and found combinations that work for them. *AIDS Treatment News* does not recommend particular therapies, but seeks to increase the options available.

Subscription Information: Call 800-TREAT-1-2

Business/Commercial: \$325/year.

Nonprofit community organizations: \$150/year.

Individuals: \$140/year, or \$80 for six months.

Special discount for persons with financial difficulties: \$54/year, or \$30 for six months. If you cannot afford a subscription, please write or call.

Back issues, and discounts for multiple subscriptions, are available; contact our office for details.

Please send U.S. funds: personal check or bank draft, international postal money order, or travelers' checks. VISA, Mastercard, and purchase orders also accepted.

To protect your privacy, we mail first class without mentioning AIDS on the envelope, and we keep our subscriber list

Medicaid to avoid interruption of treatment in early 2006, when Medicaid will no longer cover their drugs and people might not be signed up for the Medicare drug benefit in time. A revised two-page fact sheet from the Kaiser Family Foundation provides a brief overview of the Medicare program -- helpful background for understanding the additional information needed for selecting a plan.

PA-457, New Kind of Antiretroviral: Ten-Day Clinical Trial Results.....

A new kind of antiretroviral, called a maturation inhibitor, worked well in reducing viral load in a ten-day trial with HIV-positive volunteers.

No July 2005 AIDS Treatment News.....

Hurricane Katrina HIV-Related Information

September 14: Besides the thousands who have been killed, about a million people have had to leave their homes, and most cannot go back soon -- if ever. Hundreds of thousands have lost their jobs and income, and many have lost papers and medicines, or are in other states where their health coverage might not apply. An estimated 8,000 of those who had to evacuate have HIV. Here are some Web and telephone starting points for finding HIV-relevant information, especially but not only on medical care; we also include some non-HIV sites. We will update this list; for the current version, see www.aidsnews.org/katrina/.

Even if there is a search function on the Web site, it is often better to scan through all the information to find what is useful to you.

For Patients and Healthcare Professionals

www.nmac.org - The National Minority AIDS Council (NMAC) home page has a link to "detailed medical, legal, and social information and resources geared to those living with HIV/AIDS impacted by Katrina, and those who are assisting, or wishing to assist, them." Note that there are currently five pages of hurricane information, and you need to go to the bottom of each page to find the links to the other

pages.

<http://www.thebody.com/katrina.html> - See The Body's own coverage, the Snapshots series - also the HIV links, mainly medical.

<http://poz.com/katrina/index.shtml> - POZ Magazine's Katrina page.

For Healthcare Professionals and Patients

<http://www3.niaid.nih.gov/news/inthenews/katrina.htm> - excellent government site for Federal medical information, including toll-free hotline for physicians or patients to reach infectious-disease experts.

http://64.177.16.246/aahivm_blog/ or **<http://www.aahivm.org>** - The American Academy of HIV Medicine has created an emergency blog for Gulf Coast coverage. People are using it to post documents from government agencies and credible organizations. Much of the information is mainly for professionals or relief workers, but patients may find it useful as well. You can get to the blog from a link on the home page (the Web link above).

You will need to register for the emergency blog (which was hacked in early September and had to be revised). Registration is easy; you need to make up a user name and password, and supply your full name, and an email address. After you register, you will be able to choose among seven different blogs (so far). We suggest looking through all of them to find information you may need.

Currently new users should be aware of one glitch: just after you register, it may not be clear how to proceed to the information. In this case, click the title in large white type under the picture -- which is a Web link, although as of today it does not look like one.

-> Volunteer needs by clinics, hospitals, and other medical facilities: If you need volunteer HIV physicians to help with disaster relief, contact AAHIVM by sending an email to howard at aahivm dot org (reformat the email address of course).

http://www.idsociety.org/HIVMA_Template.cfm - The HIV Medicine Association has relevant links.

<http://www.tdh.state.tx.us/hivstd/meds/news.htm> - Texas, with tens of thousands of refugees from New Orleans and elsewhere,

quickly set up emergency procedures, including emergency application to ADAP for persons receiving ADAP in other states who are now in Texas due to the disaster. It also extended the time limit on emergency prescription refills (so that treatment will not be interrupted because final approval has not come through) from 72 hours to 30 days, except for Schedule II controlled substances.

For refugees arriving in Massachusetts, the state is planning to extend ADAP eligibility to those temporarily residing there. Medical arrangements may be made on arrival at Camp Edwards, or individuals may call the Community Research Initiative of New England, 1-800-228-2714, for information about applying to the Massachusetts HIV Drug Assistance Program. For general information about HIV/AIDS services in Massachusetts, call the AIDS Action Committee hotline at 1-800-235-2331.

For other states, check the sites of the state government and of local HIV/AIDS organizations. Lists of major organizations by state can be found by starting at the links above, especially www.nmac.org and <http://www.aahivm.org>

Much work remains to be done to provide access to medical care to persons forced from their homes by disaster. Medicaid, Medicare, ADAP, and the various private insurance programs are all relevant. AAHIVM, HIVMA, and IDSA (the Infectious Diseases Society of America) wrote a joint letter to Mark McClellan of the Center for Medicare and Medicaid Services, urging it to waive "certain Medicare and Medicaid requirements to allow providers in affected areas to care for patients free from the many conditions of participation in these federal programs." (The full text of the letter is at http://www.idsociety.org/HIVMA_Template.cfm.) Note: See "Simplified Medicaid Paperwork -- But..." below.

Also do your own Web searches at www.google.com or elsewhere, such as "hurricane katrina" HIV. Many AIDS sites are starting emergency information pages.

Note on Web search: You can usually find an entire document, such as a government press release, or a newspaper article that has been publicly discussed, if you have an exact quote of a short excerpt unlikely to appear in other documents. Usually one line or less is enough.

At www.google.com, search for the excerpt, in quotation marks.

Other Hurricane Disaster Resources

These are not HIV-specific, but people may want to know about them.

Reconnecting Families and Friends

A major complaint during the evacuation of New Orleans is that officials did not set up a system to help family members reunite when they were separated; many still do not know where their relatives are. Since the disaster, many private organizations have helped fill the gap by offering free, automated systems. More than 30 different "Katrina missing person sites" are currently listed at <http://msnbc.msn.com/id/9144525/>. Since there seems to be no central site, people needing to reconnect should probably use many of them.

What might be the best missing-person service does not require a computer. Air America Radio offers a public voicemail system (1-866-217-6255) that will remain until the crisis ends. It lets you file a message under your phone number -- whatever number people know as yours, whether or not that number still works. Then anyone who calls the public voicemail service and searches for your number will hear your message. (Note: if someone calls your telephone number directly, they will NOT hear the message you left on this service. They must call the service and search for your phone number there.)

Anyone leaving or receiving a message can use any telephone for a toll-free call; all they have to know is the phone number of the service, 1-866-217-6255. Most people will remember their own phone number even if they have lost all their records -- and their friends and family will have their number. All that's needed in a disaster area or refugee center (or any other location) is access to any working telephone (cell, landline, or satellite) for a couple minutes, and the number above. Note: You will be asked for a 4-digit PIN when leaving a message; this is any 4-digit number that you must save and remember in case you want to change your message later. This prevents anyone else from maliciously changing or deleting it.

We tested this system and it worked perfectly. It is provided in conjunction with VoodooVox, a voicemail service for high-call, 2(

volume industries, so it can handle the volume of calls. The huge advantage is that no computer is required; also, this system requires far less time on the equipment (the telephone) than the computer-based system require.

Simplified Medicaid Paperwork -- But...

On September 9 the U.S. Centers for Medicare & Medicaid Services announced that paperwork would be significantly simplified for persons granted "evacuee status." This should especially help those have lost their records. And "Host states must extend the expedited application process to evacuees who may be newly eligible because of new economic circumstances created by the hurricane..." For more information see <http://www.cms.hhs.gov/media/press/release.asp?Counter=1551> and <http://www.hhs.gov/news/press/2005pres/20050909.html>

But on September 10, benefits expert Tom McCormack pointed out what is missing from the announcement (emphasis in original):

"1. While it promises that states will later get the "full expected costs" in federal financing for temporary programs for evacuees and victims, *it fails to explicitly make the essential commitment to a 100% federal match* which financially hard-pressed impacted states must have.

"2. More importantly, it also *fails to waive the requirement for categorical relatedness* to qualify for Medicaid (i.e, besides being poor enough, one *also* must be aged, disabled, a member of a family with children, etc.). This means that *childless*, destitute ill and injured adults who need medical care-- if they've not yet been found formally disabled by SSA---can't get even this emergency, temporary Medicaid.

"3. And *it even fails to explicitly waive asset tests*--- which means that second automobiles, flooded/storm-damaged homes that are now vacant and unlivable, boats, small businesses, land and farm equipment---even given their greatly-reduced equity from hurricane damages---can and will still have enough value to render otherwise destitute potential Medicaid eligibles "too rich" in assets. Medicaid generally only excludes *one* vehicle of any value and only a *currently-lived-in home of any value* per family. Any other assets---including the (possibly storm-damaged, reduced value) equity of 2nd vehicles, non-lived-in (such as temporarily vacated, unlivable) real estate and bank and retirement accounts made inaccessible by the storm ---over the low state Medicaid asset levels (e.g., \$2,000/\$3,000 per family) can still cause *ineligibility*."

Debit Cards, Bank Transfers, Checks

FEMA (the U.S. Federal Emergency

Management Agency) said that it would give out debit cards for up to \$2,000 for immediate expenses such as food and transportation. But two days later it stopped giving out the cards, and announced that the money would be given by bank transfer or mailing a check instead -- which will take longer to deliver the funds. This is relief money that people are already eligible for under existing disaster relief, not additional funding; the debit card was intended to get them some money faster for immediate expenses.

People can apply to FEMA either at www.fema.gov or at 1-800-621-FEMA (1-800-621-3362); you might want to read "Help After a Disaster" at www.fema.gov. According to news reports, over 400,000 people have already applied. Disaster assistance is tax-free, and does not count as income for purposes of other federal programs at least.

The Red Cross is still giving its own debit cards for smaller amounts, up to about \$1,500 for a large family, at least at a few locations. According to one news report, it started this program three years ago, but is now having trouble keeping up with the demand.

Volunteering

There are many volunteer opportunities. Here are two that came to our attention.

Healthcare professionals and relief personnel can volunteer through a government Web page, <https://volunteer.ccrf.hhs.gov/>. There are also special instructions for volunteering as a group.

In addition, the American Red Cross has put out a call for 40,000 volunteers to help with hurricane relief.

Miscellaneous

For a short overview on preparing for future disasters, see "Some Ways to Prepare for the Absolute Worst" by Damon Darlin, *The New York Times*, September 10, 2005. It is available at www.nytimes.com -- but free registration is required, and payment is required for online articles after one week. (This article may be wrong on communication -- it basically suggests giving up unless you can afford a satellite phone. See "Communication in a Disaster: Success of Text Messages," below.)

Communication in a Disaster: Success of Text Messages

by John S. James

Police and other communication failed in New Orleans, and city officials could not reach each other. But text messages did get through. While police and city offices could not communicate at all, people in the disaster area could update their blogs by email and report to the world, using their Blackberry or other wireless email machine, often recharged by car battery since no other power was available. Reporters discovered that they could file stories from New Orleans by text messages, when they had no other means. Wireless text messages also worked when telephones did not after the recent London subway bombing.

Messages can get through when a network is damaged or overloaded because they can wait and keep trying, then transmit quickly when a connection becomes available -- while a telephone call requires that various equipment in different locations be available continuously and simultaneously. Also, text messages allow many more people to communicate than if they were using voice phone calls on the same channel. Short voice messages should also work (although maybe not as well) for those who cannot type. Clearly text messaging should be considered for future disaster communication.

People may want to learn how to use wireless email or short messages on their cell phones before a disaster occurs; sometimes the service has to be turned on and paid for before it can be used, and that may be impossible during an emergency. The U.S. is far behind other countries in popular use of wireless text communication, because here many companies charge extra fees, instead of including text messages in the basic service; therefore many customers cannot receive the messages, reducing the value of this medium for everyone.

Landline phones have traditionally worked fairly well in emergencies (a long wait for a dial tone means that the system is overloaded -- too many people are trying to call at once -- but often one can wait and get through).

Wireless could be more reliable, as there is far less infrastructure to worry about, no hundreds of miles of wires and associated equipment. The wireless hardware could be all-weather. The towers could be self-contained using batteries and satellite, and could be airlifted in if those in the area had been destroyed.

Example: A Conversation Database

A text-plus-voice message communication system could allow several people to contribute simultaneously to an ongoing conversation database, compiled separately on everyone's portable or other equipment -- and easily viewed through a choice of filters, each showing a different communication channel with the most recent messages first. For example, rescue workers could at any time choose to see all messages, or official headquarters announcements only, or official plus all messages from their own team and any coordinating teams, or perhaps all messages related to drinking water, etc. Meanwhile, anyone with the equipment could send messages to the database when necessary; headquarters would monitor all information coming in and send it out on the appropriate channels. Pressing a button or touching the screen would instantly show a new selected channel, with no delay at all since the messages would be stored on the local device and need not be re-sent.

Rescue workers could send either text or voice messages to headquarters or to their group. These could automatically be stamped with time and sender text, and headquarters could add additional text if desired, then send the messages into the same channels as the text messages above. Only one or a few people at headquarters would need to type.

Workers who were not available due to critical tasks would not have missed the messages permanently, as they could come back to them later if necessary. And even in the worst case, if all communication went out temporarily or permanently, everyone's database would still have the messages sent in all the channels so far, to help guide coordination.

A less obvious advantage of a conversation database is that, if used well, it produces a work product immediately useful to the group as a whole. Dialog conversations (like traditional phone calls) are less likely to be useful to non-participants, unless they have time to listen to the dialog.

Text-and-voice message databases could help in disasters, at least as a backup if other communication fails.

Katrina: Disaster Notes

Comment by John S. James

For a peculiar but worthwhile journalistic, well-referenced book on history and politics of disasters, see *Ecology of Fear* by Mike Davis, 1998. This book excels in outlining the racial, class, and other politics behind recent U.S. disasters and response -- which is seldom covered honestly in U.S. mainstream news. Note: Part of the book discusses fictional portrayals of Los Angeles disasters.

On race, this writer remembers a controversy from the 1960s, when a major relief organization gave new clothing to whites and used clothing to blacks; when challenged, it said its mission was to restore people to their previous standard of living before the disaster. It did change its policy.

Today, despite talk about wanting people back, it is likely that the New Orleans poor will be dispersed or moved somewhere else, and the city will be reconstituted without them -- which could quickly change one of the poorest major U.S. cities to statistically one of the richest, mainly by death and transportation. All cities want rich people and high prices, and New Orleans has the geographic importance to get them.

The central issue, for the nation and the world, is what is the future of more and more poor and middle-class people in a high-tech global economy that needs fewer and fewer workers, or can more profitably outsource their work to India or China. (While many rich people are equally unneeded by the economy, they are OK for now since they can buy what they require.)

Re-thinking is needed on designing social systems that work in disasters -- for both government programs and everyday actions of citizens. For example, recently I talked with an employee of the U.S. Environmental Protection Agency, who said the EPA had teams ready to go to help clean up environmental problems after Katrina, but they never got the official phone call, so they were still sitting idle. Maybe agencies should plan differently -- to use overall coordination if it is available, but otherwise take initiative and use

their best judgment in following a plan (it should be the same plan everyone else has -- not like what happened after Katrina, where some agencies' plans had never been seen by other agencies) -- instead of doing nothing except waiting for a call that will not come.

Now we are hearing of people getting no food or other aid as the money in their pockets runs out, while officials prevent them from returning to their homes in New Orleans to get assets and papers there. What should people do outside the disaster area -- find ways to send food or money to people they know, expect to be asked, or not wait to be asked? Work through church groups -- if they can connect with their members when everyone in a congregation has been evacuated, sometimes a thousand miles or more away, often without knowing where they were going until they were on the plane? Organize politically to make sure that people can get emergency help even if they were not evacuated by a government bus or plane, and therefore may not have papers proving that they are evacuees, but have only the money and supplies they carried with them for what they expected to be at most a few days? Time will tell how much the new "evacuee status" will help.

We don't know what to suggest, except that people across the country need to ask such questions and make plans for now and for the future. Government should provide coordination in disaster, with a plan that could work and resources as needed. But there must be backup arrangements for doing the best one can when government fails to do its job. Individuals have been extraordinarily generous in this disaster, with Americans giving more to hurricane relief so far than after the tsunami and the September 11, 2001 attacks put together. The issue is how good will can be most effective.

Fundraising: arithmetic can help with perspective. For example, local television recently covered the success of a group that raised \$1,000 for hurricane relief through a raffle -- a commendable contribution. Also at that time, Congress appropriated over \$50 billion for hurricane relief and rebuilding. A little arithmetic shows that the U.S. would have to conduct a *million* similar raffles this week, another million next week, and million more new raffles every single week for just under a year, to match the Congressional appropriation -- suggesting that many fundraising events, while perhaps good at involving people, are not efficient at producing real results toward their

official goal. (The historically very generous contributions to the Red Cross and other charitable organizations for Katrina add up to more than \$500 million so far, equivalent to over 500,000 similar raffles, but only a little more than 1% of this single Congressional appropriation for Katrina expenses -- or equal to the money cost of about half a week's war in Iraq.)

On the opposite extreme from that raffle, occasionally small groups of highly committed people make important changes that can affect the flow of billions of dollars or otherwise have major impact -- while involving only a handful of people, with little opportunity for others to join. If a way could be found to involve many people in projects that efficiently use their energy to achieve worthwhile goals, imagine what could be done toward more sensible public priorities, greater prosperity for everyone, and a more livable world.

Misleading "official" statistics: Early news reports after Katrina hit said that two people had died, giving an entirely false impression of the scale of the disaster. People expect early figures to be low, but not by a thousand times. This writer was fooled into thinking that the disaster was less severe than it was, and probably many others were fooled as well. Later, "official" death tolls in the low hundreds were widely reported in a kind of parallel reality, when it was clear that many more had died.

The widespread repetition of worse-than-useless official figures -- just because they are safe for reporters to quote, even when obviously wrong -- created a false national first impression of what had happened, and may have contributed to federal officials' difficulty in understanding the seriousness of the disaster, in the crucial early hours and days. This critical error may have stemmed from the simple fact that for a death to be recorded as official, various paperwork and other processes must be done. Official death statistics can take months or years to work their way through the system in normal conditions; here the process may have been speeded, but not all rescue workers will have filed their reports during a chaotic emergency. And with whole neighborhoods still under water, especially the poorest areas where many people had no means to evacuate, more bodies will surely be found.

For future disasters, this statistics problem might be eased if media organizations,

foundations, financial corporations, interested individuals and/or others would create instant-response teams of experts, whose job would be to produce immediate estimates and statements as events occurred -- based on all available information from all sources, and on historical experience. These would include indications of uncertainty -- and include minority reports if necessary. The incentive for accuracy would be the experts' reputations, since it would soon be clear to everyone how well they had done. Their time-stamped statements could be widely quoted and reported, in addition to or instead of official figures that clearly had no relationship to reality -- providing a far more accurate basis for public first impression, political will, and response. When major disasters were not happening, teams could be improving their methods, or practicing on less important events.

Campaign to End AIDS (C2EA)

Postpones Most Caravans, Some Events

The Campaign to End AIDS (C2EA), a new national grassroots movement led by people with HIV and community groups, will continue to organize hundreds of local events and ten cross-country caravans this fall -- although most caravans, and the five days of action in Washington, DC, will be postponed by four weeks due to the impact of Hurricane Katrina.

While responding to the urgent needs of Katrina survivors on the ground, C2EA organizers in the Gulf Coast region pledge to move forward in the fight against AIDS, which has also devastated their communities. "People living with HIV/AIDS understand how government inaction can lead to needless suffering and death," read a C2EA statement expressing solidarity with Katrina survivors.

Most caravans will now depart October 16th. Look for new dates for C2EA's Days of Action -- and info on which events will NOT be postponed -- at www.campaigntoendaids.org, or call 1-877-END-AIDS.

U.S. Conference on AIDS Will Go Forward in

Houston; New Scholarships, September 16 Deadlines

The National Minority AIDS Council has announced an extended registration deadline -- September 16 -- for the United States Conference on AIDS (USCA) to be held in Houston, Texas, from September 27 - October 2. NMAC thought carefully about postponing or canceling the conference, but decided that "those impacted by Hurricane Katrina need you more than ever. This is your opportunity to strengthen USCA's response in Houston, where so many people impacted by this tragedy have been relocated."

NMAC also announced new scholarships for organizations in areas impacted by the hurricane. "Those selected may receive one, or all, of the following: complimentary registration, hotel and travel. Requests must be submitted by 5:00 p.m. EST, Friday, September 16." For information, email conferences@nmac.org or call 1-202-483-6622.

Medicare HIV Fact Sheet: Caution re January 2006

A two-page fact sheet on Medicare and HIV is available from the Kaiser Family Foundation, <http://www.kff.org/hivaids/7171-02.cfm>

Persons on Medicare (not to be confused with Medicaid) will need to make important decisions for the new prescription-drug coverage (Medicare Part D) that begins in January 2006. This fact sheet can help them get ready.

How many HIV patients will be affected? According to the best information available, cited by the fact sheet, 19% of persons in HIV care were on Medicare as of 1996. The proportion may be larger now; a separate study of Medicare billing records found that the number of people on Medicare and receiving HIV treatment increased 50% between 1997 and 2001 (the references are on the fact sheet). Most importantly, about two-thirds of the 19 percent on Medicare were also on Medicaid; this is important because for those patients on both programs ("dual eligibles"), Medicaid drug coverage will end and patients will need to get their medications through a